



Missing Ingredients in Shared Decision-Making?

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Abstract

Shared decision-making (SDM) is a collaborative approach to making decisions in health care, and is a cornerstone of person-centered care. While providers are increasingly expected to utilize SDM in routine practice, widespread and sustainable implementation has proven difficult, especially in the care of individuals diagnosed with serious mental illnesses, and physicians and patients continue to identify barriers to effective collaboration. To date, SDM research has largely focused on the provision of high-quality clinical information from doctors to patients to the neglect of what may be the most important, and transformative, aspect of SDM—the relationship itself. In this forum, the lack of attention to the relationship in SDM research and practice will be explored, along with the relational qualities that need to be in place to implement SDM in the care of persons with serious mental illness based on the findings from a mixed-methods, participatory research project.

Keywords Shared decision-making · Treatment relationships · Patient engagement · Chronic illness care

“Just because we have mental illness, doesn't mean we can't tell if you're having a good conversation with your doctor.”

Shared decision-making (SDM), an approach in which health care providers and patients collaborate in making decisions, has been identified as a critical component of person-centered health care. With its roots in attempts to guarantee patients the opportunity to provide informed consent [1]—and bolstered by the adoption of a patient-centered approach that emphasizes self-determination and choice [2]—SDM requires a shift from traditional paternalism to a more dynamic and interactive decision-making process. As collaboration necessitates substantive

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patient engagement—for which conventional medical practice offers little guidance—and requires meaningful informed consent, unilateral decision-making by providers can no longer be viewed as an adequate or ethical guide for important decisions that have far-reaching effects in people's lives.

Despite the increased pressure to use SDM, patients and providers continue to identify barriers to sharing decision-making responsibility [3–6], making sustainable implementation difficult [7], especially in the care of persons with serious mental illnesses (SMI). To be successful, SDM requires replacing a unilateral approach to decision-making with an approach that accounts for, and hopes to counteract, imbalances of power in physician-patient relationships through prioritizing and supporting patient self-determination. While operationalized in a variety of ways, SDM is said to involve three key components: (1) a mutual exchange of information in which patients educate providers about their personal values, preferences, and goals and providers provide high-quality clinical information tailored to these needs in a way that is readily understandable; (2) providers support patients (and potentially important others in patients' lives) in considering their options; and, (3) arrive at a mutually agreed upon plan for care [8, 9]. Our research has suggested that while these components may be necessary, they may be insufficient to ensure that people are meaningfully engaged in the SDM process.

In a mixed-methods participatory study, we are developing a tool to assess relational quality and collaboration to support physicians and patients. During the course of this work, we had the opportunity to talk to doctors and patients in qualitative interviews, focus groups, and concept mapping sessions, about what was most important to them in their relationships with one another. Based on findings from this research, we will describe four areas—the provider-patient relationship, targets of SDM intervention, focus decisions, and definitions of success—that have the potential to increase the utility, and the chances of implementation, of SDM (see Table 1). Specifically, we explore whether respect—an often cited, yet just as taken for granted, relational quality—may be a particularly challenging, if not missing, ingredient in realizing the ways SDM can transform routine mental health care.

A Relational Model of SDM

Provider-Patient Relationship While a collaborative relationship has been conceptually linked to SDM [8, 9], and even considered a critical condition for its use, it is often assumed by current models, with little research to guide providers in creating such relationships in practice. Building collaborative relationships that can sustain SDM may require a more systematic and intentional framework in order to be useful in everyday practice. For example, relational factors are often discussed solely in terms of creating a safe environment, gaining patient trust, and building rapport, and are relegated to amorphous concepts. The relationship is not only a means to an end, however, and should remain a primary, central concern throughout the decision-making process.

Building collaborative relationships is a difficult and complicated matter in mental health care. People with SMI have complicated paths to care and may have experienced suboptimal care, coercion, and a treatment environment that focuses more on illness management than on helping them achieve personal goals. These experiences can result in mistrust of mental health care and perceptions that one's concerns are not taken seriously by providers. Thus, it is of utmost importance to create an environment in which patients feel safe enough but also are empowered to engage in the decision-making process as equal partners.

Table 1

Goal of SDM intervention	<i>Reduce imbalance of power in the doctor-patient relationship through supporting patient self-determination and agency in health care decision-making</i>	
	Existing SDM models	Relational SDM model
1. Target of intervention	Reduce informational asymmetry between patients and physicians; Increase information sharing	Increase elements of support, empathy, and mutual trust to facilitate information sharing; informational asymmetry is only one aspect of doctor-patient interactions that maintain this power imbalance
2. Definition of success	Define success in terms of outcome, namely a mutually agreed upon decision regarding care	Define success in terms of process and quality of decision-making—involve elements of support, empathy, and trust
3. Focus of decisions	Decisions about treatment	Decisions about accommodating for illness in their day to day lives, assimilating new aspects of identity related to chronic condition, and continuing to occupy meaningful and satisfying roles in their families and communities along with treatment decisions
4. Doctor-patient relationship	Relationship is of secondary importance to information exchange and treatment decisions; sole focus on patient trust and safety	Relationship is of primary importance along with trust in physician expertise and exchange of information; patients feeling supported, respected, heard, and engaged before (and during) formal SDM process

Our research has identified a tension between treatment and support. For example, patients wanted to feel confident in their physicians' expertise and receive high-quality care but feeling supported and respected were important as well. When not present, patients did not value the experience, doubted the expertise and professionalism of the physician, disengaged from treatment, and did not feel they could be honest with providers. Feeling respected and supported involved a variety of factors, including taking the patient's perspective seriously, reflecting patient preferences, needs, values, and goals, and demonstrating a genuine concern for the patient's well-being. When patients experienced these relational factors, they described feeling as though they were meaningfully engaged in decision-making and had an amount of say in their care that was in line with their preferences. While having limited time is seen as a major barrier to effective health care relationships and SDM, the findings of our research thus far indicate that this is feasible within the current realities of clinical care, as some patients and physicians indicated they have engaged in SDM in this manner.

Targets of SDM Interventions SDM frameworks have been largely operationalized in the form of decision aids to assist providers in providing high-quality, thorough clinical information. As a result, much of current SDM thinking addresses only one asymmetry in the provider-patient relationship—the informational asymmetry. In many respects, this makes good sense—when patients have enough medical information, they can participate more in decision-making regarding their care.

Yet medical information alone is not enough to address the overall asymmetry between physicians and patients, as a patient's lack of medical knowledge is only

one of many ways this asymmetry is maintained. While decision aids have resulted in advances in care, the focus on decision aids may have obscured relational factors that also result in existing power differentials. First, decision aids only address half of the informational asymmetry and there is less research to support eliciting patient preferences, values, and goals. Second, our research suggests that rather than focusing on the reciprocal exchange of information between physician and patient, SDM models might be enhanced by targeting the feelings underlying honest and open sharing of information—feelings of support, empathy, and understanding. When patients experienced such feelings, they also described having a satisfying amount of say in their care.

Focus of Decisions Decisions about care are crucial but they are not the only decisions relevant to recovery. We have found that patients are concerned with a variety of issues, including accommodating for illness in their everyday lives, continuing to occupy satisfying roles in their families and communities, discrimination, financial concerns, and others. Furthermore, patients felt understood when physicians saw them in the contexts within which they were living rather than defining them narrowly in terms of the health conditions they were experiencing. When patients were seen as more than their diagnoses, people described being better prepared to engage in decision-making. Focusing on the other half of information exchange in which patients share important aspects of themselves (e.g., needs and values), requires providers to ensure a safe and comfortable enough relationship in order to elicit these crucial components of SDM. As decision aids have helped providers communicate clinical information, tools could be developed to help create a safe enough relationship to elicit patients' preferences and goals.

Definitions of Success Most models of SDM define success in terms of a specific outcome, namely a mutually agreed upon treatment decision. While physicians and patients agreeing with one another is important, SDM research has not provided an adequate framework to assist in the sharing of the decision-making process that could result in such an outcome. We may need first to target the process and quality of the relationship and expand our notion of success to include relational factors. Including components of respect, trust, empathy, and support in the definition of success equips providers with discrete, achievable, and measurable goals to guide the decision-making process. As these factors are already part of high-quality clinical care, SDM can build upon existing strengths.

Research also suggests that mutual agreement may be more complicated than it seems and that the notion that providers and patients should (eventually) agree may be more in the service of making providers comfortable ceding some control and tolerating some risk rather than truly engaging patients in the decision-making process. [10, 11] Moreover, it may be unreasonable for providers to operate from the assumption that patients will relinquish control over decisions that have far-reaching effects on their daily lives [12]. Additionally, our research suggests that some patients did not disclose when they felt uncomfortable with the decision-making process. Instead, they disengaged from care in more subtle ways (e.g., not taking medications or coming to appointments). However, when a collaborative relationship existed, patients felt as though they could take part in decision-making and had room to disagree with providers. While a provider may ultimately disagree with a patient's decision, the person ultimately chooses and has to live with the outcome of the decision. SDM should thus support the development of empathy, enabling providers to understand patients' rationales for their decisions.

Conclusion

Recently, researchers have called attention to some missing ingredients of SDM, including the need for integrating patient narratives into decision-making [13], fostering open communication [14], and offering care and conversation along with high-quality information [15]. While these ingredients may improve decision-making, SDM is likely to continue to flounder, and remain difficult to implement, without revising the conceptual model on which it is based. Meaningful collaboration around decisions may require models that prioritize caring, support, and self-determination rather viewing them as distal aspects of the decision-making process. Without such reform, persons with SMI, who may likely benefit the most from collaborative relationships, will continue to be neglected in realizing a more person-centered health care environment.

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Compliance with Ethical Standards

Conflict of Interest The authors declare no conflicts of interest.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent Informed consent was obtained from all individual participants included in the study.

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Mary K. Snyder is a business woman, author, musician, and healthcare advocate. Over the past 15 years, she has been living with multiple chronic illnesses and navigating the healthcare system. Through her personal experiences, she found her focus turning to better ways in which to relay information to care providers. Her work in shared decision-making aims to assure that all persons have the ability and opportunity to be heard by their providers and help providers come to a better understanding of the patient needs.

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